# UNITED STATES DISTRICT COURT DISTRICT OF MAINE

CONSUMER ADVISORY BOARD, et al. Civil No. 91-321-P-

Plaintiff V. ROBERT W. GLOVER, et al. Defendants

Upon the joint motion of Plaintiffs and Defendants, it is hereby ordered, adjudged and decreed:

- I. Legal Parameters
- 1. This decree is entered into jointly by all parties to this action.
- 2. By entering into this consent decree, the parties agree, and the Court so orders, that the original decree entered in Wuori v. Concannon, Civ.No. 75-80 SD (July 12, 1978), including Appendices A and B, is hereby terminated and replaced with this decree. The Plaintiffs, in agreeing to terminate Appendix A, acknowledge that the present state and federal regulations governing ICF/MR institutions, which include Pineland Center, adequately address the health and safety needs of Pineland Center residents, and the Defendants agree that, in the event that changes in those regulations during the life of this decree diminish any health and/or safety protections afforded to class members, they will comply with the higher standard. By entering into this decree, the Plaintiffs do not take a position regarding Defendants' plan to close Pineland Center.
- 3. In entering into this decree the Defendants acknowledge the continued jurisdiction of the Court in this matter. The purpose of this new decree is to bring into being a new document that is more relevant to Wuori class members, both in light of the Defendants plan to ultimately close Pineland Center and due to changes in the philosophy and delivery of services to individuals with mental retardation in the 1990s.
- 4. By entering into this decree, the Defendants make no admission of liability and do not waive any defenses available to them regarding any claim that exists now or in the future concerning the potential applicability of this decree to individuals not currently class members under the Wuori consent decree.

#### II. Class

The class consists of all persons who were or have been involuntarily confined residents of the Pineland Center at any time on or after July 3, 1975, or who were conditionally released from Pineland and in community placements at any time on or after July 3, 1975, exclusive of those individuals admitted to Pineland for a specific medical service at Benda Hospital or for respite care for less than 21 days.

#### III Notice to Class

- 1. Pursuant to F.R.Civ.P. 23(e), Defendants shall mail individual notices to all class members or their guardians, or, when a class member has a public guardian, to his/her correspondent. These notices shall state, in simple language, that the current litigation has ended, with the major result being the creation of a 'new.' consent decree. This notice shall contain a very brief outline of the provisions of the decree. This notice afforded to the class shall inform class members that if they desire a copy of the decree, they can secure one by requesting one from their Individual Support Coordinator. It shall also notify them that if they have any questions, they may contact one of the three Plaintiffs' attorneys, whose addresses and telephone numbers shall be listed in said notice.
- 2. Finally, Defendants shall also post notice of the new decree at Pineland Center and in each DMR office and shall ensure that copies are available upon request.

#### IV. Enforcement.

- 1. Defendants are ordered and enjoined to take all actions necessary to secure implementation of this decree in a prompt, orderly manner.
- 2. Defendants shall delegate among themselves and their subordinates responsibility for the appropriate and relevant actions necessary to implement this decree, including coordination with other State agencies as is necessary and proper to the full implementation of this decree.
- 3. This decree shall be applicable to and binding on the defendants and their successors, their agents, servants, and employees. In addition, Defendants shall include in every future contract requiring an agent or independent contractor to perform duties that would otherwise be performed by Defendants or their employees, a clause requiring the agent or independent contractor to perform these duties in accordance with the requirements of this decree insofar as it may be relevant to said contracts.
- 4. This decree shall remain in full force and effect until terminated by order of the Court. This shall not occur until at least one (1) year from the date there are no longer any class members residing at Pineland Center. Subsequent to that date, Defendants may move for termination of the decree. The foregoing notwithstanding, any party may, at any time, apply to this Court for such orders as may be necessary or appropriate. Should issues regarding the interpretation or implementation of this decree arise, the parties shall endeavor in good faith to resolve such disputes as may arise between them. To the extent that the parties believe they are unable to resolve such disputes, the parties may apply to the Court for either a conference of counsel with the Court, or in the alternative, for use of a Magistrate Judge as a mediator in order to attempt to resolve their differences prior to the submission of any formal action before the Court.
- 5. Defendants shall keep the Plaintiffs regularly apprised of their legislative proposals and initiatives, including budgetary proposals, and specifically provide the Consumer Advisory Board and counsel for the Plaintiffs with copies of any formal legislative proposals and initiatives as soon as they are publicly available. When the Governor's budget is publicly available, Defendants shall provide Plaintiffs with copies of the Commissioner's final budget proposals to the Governor.

- 6. The parties shall periodically consult with each other regarding legislative proposals of mutual concern. Upon notice from Defendants that they intend to seek termination of this decree, the parties shall convene a joint committee to explore mutually acceptable legislative proposals for the future provision of services to Maine citizens with mental retardation.
- 7. A termination of this document may occur when Defendants achieve compliance with the terms of this decree. Compliance may be achieved by meeting the following criteria:
  - (a) by showing substantial compliance in a numerical sense with the terms of this decree;
  - (b) by having mechanisms in place to assure future compliance; and
  - (c) by showing a demonstrable commitment to achieving compliance.
- 8. Plaintiffs reserve the right to request such costs and attorneys fees as this Court deems reasonable and appropriate. Defendants reserve the right to oppose such motions.

## V. Statement of Principles

Service delivery to members of the Pineland class, and the interpretation and enforcement of this decree, shall be guided by the following principles:

- 1. Class members have the same rights as all citizens, including the rights to live, work, and enjoy recreational opportunities in the community.
- 2. All services provided should have the goal of maximizing growth, development, and social integration into the community.
- 3. All services must acknowledge and enhance the role of the family, as defined by the individual, as the primary and most natural care giver.
- 4. Community integration is achieved by connecting individuals and families with local and generic supports within the community.
- 5. Planning for community services shall be based upon the ongoing process of individualized assessment of individual/family strengths, needs, and preferences.
- 6. Services provided to persons with mental retardation shall enhance their opportunity to assume maximum control over their lives.
- 7. Real work for real pay, in integrated settings, shall be the cornerstone of all vocational and employment services.
- 8. Residential services should be small, integrated, and community based. Services designed to support individuals in their own homes must become the primary objective of the delivery system.

- 9. The first preference for providing residential services is in the natural home with ongoing necessary supports.
- 10. Connections in other areas of life such as friends, recreation, and spirituality need to be considered in order to promote quality of life.

### VI. Definitions

- 1. "Advocate' means employees of the Office of Advocacy unless a person who has no guardian, or a person's guardian, has designated another individual or organization to be the advocate, in which case it means that individual. A public guardian shall consider the wishes of the person in the selection of an advocate.
- 2. 'Class' means all persons who were or have been involuntarily confined residents of the Pineland Center at any time on or after July 3, 1975, or who were conditionally released from Pineland and in community placements at any time on or after July 3, 1975, exclusive of those individuals admitted to Pineland for a specific medical service at Benda Hospital or for respite care for less than 21 days.
- 3. 'Commissioner' means the Commissioner of the Maine Department of Mental Health and Mental Retardation or his/her successor.
- 4. 'Community Placement' or 'residence' means a residence in the community in a group home, foster care home, natural or family home, apartment or house, boarding home, or similar residential facility coupled with a program element adequate to meet the person's individual needs.
- 5. 'Consultant' means an individual, agency, firm, or organization that is independent of the Department of Mental Health and Mental Retardation, although not necessarily independent of other state agencies or departments.
- 6. 'Consumer Advisory Board' means the Consumer Advisory Board maintained by this decree in Section XIII.
- 7. 'Correspondent' means an individual designated as next friend of a person according to the following order of preference and principles:
  - a. In the first instance, the person's private guardian,
  - b. If the person does not have a guardian or has a public guardian, the person's parents or parent;
  - c. If the parents are deceased or their whereabouts cannot, with due diligence, be ascertained and they have failed to designate an appropriate representative, the relative, if any, in closest relationship with the person who has, at least once within the previous year, manifested interest in the person by communicating with DMR regarding the person; or
  - d. If no correspondent can be designated according to section a, b, or c above, or if the legal guardian, parent, or relative is unable to exercise his/her rights hereunder because of age, illness, distance, or some other compelling reason, the correspondent shall be an individual designated by the Consumer Advisory Board.

- e. Any person who does not have a guardian can refuse the designation of a correspondent, can choose the individual to be designated as his/her correspondent, including the Consumer Advisory Board, or can revoke the designation of any correspondent.
- f. Any notices required by this decree to be sent to a correspondent shall inform the correspondent of his/her right to designate the Consumer Advisory Board to act for him/her if for the reasons stated above he/she is unable to exercise his/her rights. Any designation of the Consumer Advisory Board shall remain in effect until revoked by the correspondent or by a person who has no guardian.
- 8. 'Crisis' means any incident, behavior, activity, or pattern of activity which could lead to the loss of a person's residence, program, or employment.
- 9. 'Defendants' means the Commissioner, the Director, and the Superintendent of Pineland or his/her successor.
- 10. 'Department' means the Department of Mental Health and Mental Retardation.
- 11. 'Director' means the Director of DMR or his/her successor.
- 12. 'DMR' means the Division of Mental Retardation.
- 13. 'Family', for purposes of the family support program, in the first instance means the person's biological or adoptive parents. It may also include, where appropriate, individuals with whom the person resides, or intends to reside, and where the individual has a significant unpaid role in the person's well-being.
- 14. 'Guardian' means the legal guardian of a person, including a public guardian.
- 15. 'Hearings Unit' means the State Administrative Hearings Office chosen by Defendants to provide hearing officers to preside at appeals hearings on grievances.
- 16. 'ICF/MR' means an intermediate care facility for individuals with mental retardation.
- 17. 'Individual Support Coordinator' means regional staff of Defendants with responsibility for coordinating a person's planning process and services according to this decree. At least 75% of Individual Support Coordinators shall have professional qualifications.
- 18. 'Individual Support Teams' means two or more persons whose responsibility it is to deliver a crisis prevention or intervention service to a person who needs it.
- 19. Individuals 'who support' persons with mental retardation means providers, correspondents, family members, advocates, friends, and employees or contractees of the Department of Mental Health and Mental Retardation.
- 20. 'Mental health provider' means a professional working in a mental health field.
- 21. 'Person' means a class member.

- 22. 'Pineland' means Pineland Center, Pownal, Maine.
- 23. "Plaintiffs" means the Consumer Advisory Board, the plaintiff class, and/or, where appropriate in context, counsel for the plaintiff class.
- 24. 'Plan' means the individualized plan created according to the process outlined in Section VII of this decree.
- 25. 'Planning team" means the person, his/her guardian if any, the person's Individual Support Coordinator, and other individuals chosen or identified in accordance with Section VII of this decree.
- 26. 'Professional' means any individual possessing appropriate licensure, certification, or registration to practice his/ her discipline in the community. Where licensure, certification, or registration is not required, 'professional" shall mean a person possessing a Master's Degree in the appropriate discipline or a person possessing a Bachelor's Degree in the appropriate discipline and three years experience providing support for persons with mental retardation or three years experience in a related human services field.
- 27. 'Providers' means any individual or organization providing supports to persons or their families.
- 28. 'Region' or 'Regional' means the division of the State of Maine by DMR into districts for administrative purposes.
- 29. 'Regional Manager' means the professional who heads the appropriate regional office.
- 30. 'Representative", in the context of grievance and appeal rights, means the guardian, correspondent, and/or advocate of or for a person.

## VII. Personal Planning Process

- 1. Within eighteen months of the date of this decree, Defendants shall give each person the opportunity to engage in a person-centered planning process where the needs and desires of the person are articulated and identified. Personal desires and needs shall be recorded without respect to whether those desires are reasonably achievable or the needs are presently capable of being addressed. In cases where resources required to address identified needs or desires are not available, the planning team shall develop an interim plan based on available services which:
  - a. addresses the needs or desires as nearly as possible, and
  - b. identifies steps toward meeting the person's actual identified needs.
- 2. The planning process shall include participants chosen by the person and others who can be anticipated to assist the person in productive pursuit of articulated desires and identified needs. The planning process shall minimally include the person, his/her guardian, and his/her Individual Support Coordinator, with participation and/or input by friends, service providers, correspondents, advocates, and others. Unless the person objects, the correspondent and advocate shall always be invited to the

planning meeting and to otherwise participate in the planning process. The Office of Advocacy shall receive notice of the formal commencement of all planning processes.

- 3. Each person shall be offered a planning process at least annually. Notification of this offer shall be given to the person's guardian, if any, and, unless the person has no guardian and objects, to the person's correspondent and advocate. Any refusal of the annual planning process shall be documented in the person's records.
- 4. Whenever needed or desired, the person or another member of the planning team may initiate a review of the person's plan.
  - a. The review shall be done by meeting together or by other means sufficient to address the needed or desired changes.
  - b. Any review shall always include the person and his/her guardian, if any. The Individual Support Coordinator shall be part of the review process. Unless the person has no guardian and objects, notification of any review shall be given to the person's correspondent and advocate.
  - c. Events which shall lead to plan review include, but are not limited to, use of crisis intervention services, and use of physical restraints, and events which could lead to loss of a person's home, job or program.
  - d. Other events which shall lead to a plan review shall be identified by the planning team.
- 5. As part of the Individual Support Coordinator's monthly contact with the person, he/she shall inquire about any changes which have occurred, and any desires and needs that may affect the person's plan and which may cause a need for review.
- 6. The Defendants shall have responsibility for assuring that the above provisions are carried out and for maintaining suitable records of activities under each person's plan.
- 7. 'Suitable records' as specified above shall include each of the following elements:
  - a. Records shall record personal needs and desires without respect to whether the desires are reasonably achievable or the needs presently capable of being addressed.
  - b. The person's written plan shall be provided to the person, his/her designees, and all persons identified as responsible for any significant activity pursuant to the planning process.
  - c. Defendants' activities and findings relating to the person's plan.
  - d. On a form clearly designated for the purpose of identifying unmet needs, a listing of each service or activity which cannot occur or is not occurring pursuant to a person's plan. Unmet needs shall be documented on a monthly basis by DMR and shall be collated quarterly and utilized for appropriate development activities on a regional and statewide basis. These findings shall be made available to the Consumer Advisory Board.
- 8. Given the above requirements for the planning process and for formulating suitable records, the Defendants shall develop procedures, including forms, which are simple to understand and use and are the same throughout the state. These procedures and forms shall be provided to Plaintiffs within six months of the date of this decree for their review and comment.
- 9. Within four months of the date of this decree, the Defendants shall prepare a comprehensive manual describing the processes to be followed in implementing a person-centered planning process. Plaintiffs

shall be given an opportunity to review the manual, to make comments on it, and to meet and discuss with Defendants any disagreements on its contents. Defendants shall provide a written explanation regarding their position on any manual items which are not agreed to following that meeting.

#### 10. The manual shall include:

- a. Provisions for the person to indicate his/her planning preferences.
- b. Provisions for preplanning prior to commencement of the formal planning process.
- c. Provisions for written documentation of all actions agreed to be carried out and appropriate and timely distribution of such documentation
- d. Provisions for identifying and addressing a person's residential needs, Professional service needs, program or employment needs, respite, leisure time needs, spiritual needs, and family support needs.
- e. Provisions for identifying a person's needs and desires irrespective of Defendants' ability to satisfy those needs and for developing an interim plan when needs cannot be met.
- f. Suggested guidelines for dealing with issues regarded by a person as private or sensitive.
- g. Suggested methods for assisting a person to identify an unpaid friend who can participate in his/ her planning process.
- h. Provisions for assuring due process protections in the event that limiting or abridging a person's rights is being considered.
- i. Provisions for dispute resolution, grievances, and appeals.
- j. Provisions for assuring each person's satisfaction with the quality of supports he/she receives.
- k. Provisions for assuring that planning meetings be held both prior to and subsequent to the planned move of a person to a new residence in order to coordinate supports and services and to evaluate the person's satisfaction with the change.
- 11. Within six months of the date of this decree, the Defendants shall design and begin delivering training programs on the person centered planning process. Training will be provided for persons, staff of Defendants, contracted persons who have responsibility under this decree, families or friends of persons, correspondents, and providers of services. Professionals and interested others who wish to participate in provided training shall be permitted to do so. 12. At a minimum, training shall consist of the following:
  - a. The vision and goals of the new planning process.
  - b. Methods to enhance collaboration and teamwork among participants in the process.
  - c. In detail, the processes to be followed under the new planning process.
  - d. Methods to be followed to assure regular and proper documentation of results and progress towards meeting needs following each person's planning process.
  - e. Methods to ensure that unmet needs are made known to the administrative and resource development staff of Defendants, in a useful format.
  - f. Periodic review of training effectiveness and the design and delivery of revised training on an annual basis.

#### VIII. Crisis Prevention and Intervention

- 1. Defendants shall provide crisis prevention and crisis intervention on a statewide basis.
- 2. Crisis prevention services shall include at least the following elements:
  - a. Appropriate training for staff and families who support persons during times when crisis prevention or intervention may be necessary;
  - b. Respite services to relieve the stress experienced by families and staff who provide direct support;
  - c. Available beds in privately operated respite homes as described in Section VIII(3)(c) below; and
  - d. Individual Support Teams to address the needs of persons in their homes or places of work by providing assessment and consultation before a crisis occurs, providing in-home staff support where necessary to prevent a crisis, helping to identify professional services available in the community, and linking people with professional services appropriate to meet their needs.
- 3. Crisis intervention services shall include at least the following elements:
  - a. Individual Support Teams to provide crisis intervention services at a person's home, program, or workplace when prevention efforts are not successful and to assist with admission to a respite home or a home supporting persons in crisis in the event that intervention at the person's home, program, or workplace is inadequate;
  - b. State operated homes supporting persons in crisis with no more than two persons in each home, with a total statewide capacity of 12 persons;
  - c. Privately operated respite homes with a total statewide capacity of at least 12 persons at a time.
- 4. Individual Support Teams may include both state and privately employed members. Team members shall be appropriately trained and will be selected to address specific needs of a person in need of crisis prevention and intervention services. Both trained direct support staff and, as needed, licensed professional staff will be available to participate in Individual Support Teams.
- 5. By December 30, 1995, the Defendants shall develop procedures to outline the composition and operation of Individual Support Teams. The composition of Individual Support Teams shall be based on the needs of the person. Plaintiffs shall be given an opportunity to review the procedures developed by Defendants, to make comments thereon, and to meet and discuss with Defendants any disagreements about the procedures. Defendants shall provide a written explanation regarding their position on any points which are not agreed to following that meeting.
- 6. Defendants shall hire 30 qualified people to be part of Individual Support Teams located throughout the state. The first 15 people shall be hired by December 30, 1995, and the second 15 people shall be in place by June 30, 1996. The location of these 30 people shall be initially and always based on data collected that assesses where the need is.
- 7. Defendants shall provide training for the Individual Support Teams which shall include at least the following elements:
  - a. Identification of the causes of crises.
  - b. Crisis prevention techniques.
  - c. De-escalating a crisis.
  - d. Assessment of the current needs of a person in crisis.

- e. Development of interim plans to stabilize a person in crisis.
- f. The coordination of professional services and resources.
- 8. Defendants shall provide training for staff and families which shall include at least the following elements:
  - a. Identification of the causes of crises.
  - b. Crisis prevention techniques.
  - c. De-escalating a person in crisis.
  - d. Identification and location of professional resources and services.
- 9. Defendants shall provide training for mental health providers, general health providers, law enforcement officials, and others involved in supporting a person during a crisis. Training shall include at least the following elements:
  - a. An introduction to mental retardation.
  - b. Differences between mental retardation and mental illness.
  - c. Identification and location of appropriate professional resources and supportive services to meet the person's specific needs.
  - d. Training in the behavioral rules promulgated and maintained pursuant to Section XVI(7) of this decree.
- 10. All initial training under this section shall be completed by December 30, 1995, and ongoing training shall occur at least annually thereafter.
- 11. Admission of a person in crisis to any respite home or home supporting persons in crisis shall occur only if in-home intervention fails, and the person's Individual Support Team, after seeing the person, determines that immediate movement is necessary for the health and safety of the person or to prevent jeopardy to his or her current living arrangement. The planning team may specify exceptions to this process.
- 12. State operated homes supporting persons in crisis shall be available when admission to a private respite home cannot meet the needs of the person or if emergency involuntary admission becomes necessary.
- 13. Defendants shall not routinely use law enforcement entities to transport persons in crisis and shall do so only as recommended by a person's plan or when absolutely necessary to provide for the safety of the person or others.
- 14. Two person homes supporting persons in crisis, for a total of 6 persons, shall be in place by December 30, 1995, and two person homes supporting persons in crisis, to accommodate 6 additional persons, shall be in place by June 30, 1996.
- 15. Any stay in excess of 10 days in a state operated home supporting persons in crisis shall require approval of the Director or his/her designee.

- 16. Defendants shall assure that persons in crisis who are in need of mental health supports receive them. Mental health supports shall include at least access to a mental health provider on the Individual Support Team, the availability of inpatient treatment when indicated, psychiatric services, and mental health aftercare services.
- 17. By December 30, 1995, a mechanism for documenting post-crisis review shall be developed for significant providers and supporters to identify variables and possible causes of the person's crisis and to plan what to do differently with the person in the future. A post-crisis review shall occur no more than 10 working days after any out-of-home crisis placement.
- 18. Defendants and Plaintiffs shall assess annually the outcomes of the use of crisis prevention and intervention services to determine their effectiveness.

#### IX. Professional Services

- 1. The Defendants shall assure the provision of services of physical therapists, occupational therapists, psychologists, speech therapists, and other professionals on a statewide basis in order to meet the needs of each person, based on his/her plan.
- 2. Defendants shall provide the following Medical and Dental Services:
  - a. The Defendants shall assure that each person shall receive medical and dental services including at least an annual medical and dental examination unless otherwise recommended by the physician. An eye examination shall be provided as needed and in accordance with each person's plan. A guardian of a person shall approve all medical and dental treatments including the use of all medications provided to the person.
  - b. Glasses shall be provided to a person unable to pay for them.
  - c. The planning process shall designate an individual to monitor the quality of medical and dental care a person receives. If continuing problems with treatment arise, that individual shall secure a second professional opinion or take other appropriate action.
  - d. Defendants shall identify through the personal planning process those persons who have a need for mental health services in community hospitals or other settings and shall develop protocols to assure equal access to those services by persons with mental retardation. Defendants shall enter into agreements with private providers and/or mental health centers in communities to ensure such needs are met.
  - e. When psychotropic medications are prescribed for a person, the community professional standard of usage shall apply.
  - f. Individuals who support persons receiving psychotropic medications shall be informed of significant positive and adverse effects of medication and shall document all effects that are observed. All persons receiving psychotropic medication shall have their medication reviewed at least every six (6) months.

- 3. Defendants shall ensure that sufficient transportation is available so that persons can attend all recommended program activities and professional services and so that recreation, shopping, and other community activities are reasonably accessible to persons.
- 4. Defendants shall provide the following Psychology Services:
  - a. Psychology services shall be available and provided as recommended by each person's plan.
  - b. Qualified psychologists shall be available to work with Individual Support Teams.
- 5. Defendants shall provide the following Communication Services:
  - a. Communication services and reasonable equipment needs shall be provided as recommended by each person's plan.
  - b. Hearing aids shall be provided as needed and shall be maintained in good working order.
  - c. Where appropriate, persons who are deaf or hard of hearing and persons with neurological or physical damage precluding the acquisition of speech shall be taught sign language or an alternate communication system. The Defendants shall ensure the provision of support and training for parents and others who support persons who use alternative communication systems.
- 6. Defendants shall provide the following Social Work Services:
  - a. Individual Support Coordinators shall have an overall maximum caseload ratio of 1:35 in each region.
  - b. Individual Support Coordinators shall perform the following types of services for each person residing in the community:
    - i. Case management: The coordination of services provided to each person to insure that the services recommended in the person's plan are being provided.
    - ii. Follow up and follow along: At least monthly contact with each person in order to assure that quality of services and consumer satisfaction are maintained at a high level.
    - iii. Record keeping.
  - c. There shall be at least one regional supervisor for each regional office. Supervisors shall be qualified professionals.
  - d. A person's program site and home shall be visited by the Individual Support Coordinator at least twice per year and more frequently when necessary or as otherwise designated in the person's plan.
  - e. There shall be a uniform system of records kept by the regional office for each person, developed and maintained under the supervision of the Individual Support Coordinator assigned to each person.
  - f. The Individual Support Coordinator shall review and update the records at least monthly.
  - g. A copy of those portions of a person's records relevant to the daily routine and the health and safety of a person shall be maintained at the person's home and program. Information shall be incorporated in a person's record in sufficient detail to enable those persons involved in a person's plan to provide effective, continuing services. All entries in a person's record shall be legible, dated, and signed by the individual making the entry. The confidentiality of all records shall be respected.
  - h. The records maintained by the Individual Support Coordinator shall include at least the following:
    - i) identification data including guardianship status.
    - ii) the name and address of the person's correspondent.
    - iii) relevant family data including family visits and contacts.
    - iv) the person's educational background and employment records.

- v) the person's complete medical record including medication history and current medication regime.
- vi) an inventory of the person's life skills.
- vii) a copy of the person's plan and any modifications and evaluations thereof, with any appropriate. summary to guide home and program staff in implementing the plan.
- viii) the findings made in annual reviews of the person's response to his/her plan, with directions for modifications prepared by any professionals involved in the person's plan.
  - ix) a physical description and photograph of the person.
  - x) observations on the quality of supports and services being provided. Any problems identified shall be noted in the person's records by the Individual Support Coordinator at the time of the visit or shortly thereafter.
- 7. The Defendants shall also employ at central office a training supervisor to oversee statewide and regional training in accordance with the requirements of this decree. The Defendants shall also employ a training coordinator in each region to coordinate and provide direct training in accordance with the requirements of this decree.
- 8. On a statewide basis, by July 1, 1995, the following liaison professionals shall be retained: a physician skilled in psychotropics, a dentist, an occupational therapist, a physical therapist, a communications expert, an educator, and a Medicaid specialist to assist the above professionals and to act as a liaison with the Department of Human Services.

# X. Resource Development

- 1. The Defendants shall assist persons who have needs identified by their planning process to obtain housing, employment (or other meaningful occupation), medical and other professional or therapeutic services, recreational and vocational opportunities, and religious and educational services.
- 2. In assisting persons who wish to change their current home, Defendants shall be guided by the following principles, unless an exceptional reason exists for not doing so:
  - a. a smaller place in which the person feels at home;
  - b. the proposed home is in proximity to community activities and resources in which the person wishes to involve himself / herself;
  - c. the proposed home is in reasonable proximity to the person's family, correspondent, or close friends with whom visits are likely to occur;
  - d. the home, or its location, will provide the person opportunities for personal growth and development and for the exercise of personal autonomy.
- 3. Exceptional reasons for contradicting the above principles shall include only the following:
  - a. the person, or if applicable the person's guardian, clearly desires to make a choice which is not based on the above principles, and the exercise of that choice will not pose any substantial risk of harm to the person;
  - b. no currently available home fully meets the above listing of principles, complies with the person's choice, or is designated in the person's plan.

- 4. In the event that a person's home was chosen pursuant to 3.b., Defendants shall assure that a full description is made of a more desirable home for that person. That description shall be used for the purposes of locating or developing the described home.
- 5. Defendants shall continuously locate, secure, fund and develop homes identified pursuant to paragraph 3.b.
- 6. On an annual basis, Defendants shall assure that new homes are developed for one-third of persons whose current homes are provided under paragraph 3.b. Priority development shall occur for those persons who have waited for 24 months or longer.
- 7. Defendants shall continuously retain the services of persons experienced, skilled, and trained in the development of housing and employment resources as follows:
  - a. Across the state, a minimum of ten regional resource development staff;
  - b. In the Central Office, one Resource Developer with access to professional assistance in the areas of law, zoning, financing and federal housing and employment program requirements.
- 8. In assisting persons who wish to change their current employment or other activities, Defendants shall be guided by the following principles unless an exceptional reason exists for not doing so:
  - a. Employment or other activities that foster a person's independence and self-sufficiency are to be preferred.
  - b. Employment or other activities that are appropriately remunerative are to be preferred.
  - c. Employment or other activities that provide the person a sense of meaningfulness and self-esteem are to be preferred.
  - d. Employment or other activities that are integrated with the broader community in which those activities occur are to be preferred.
- 9. Exceptional reasons for violating the above principles shall include only the following:
  - a. The person, or if applicable the person's guardian, clearly desires to make a choice that is not based on the above principles, and the exercise of that choice will not pose any substantial risk of harm to the person.
  - b. No currently available employment or other activities fully meets the above listing of principles, complies with the person's choice, or is designated in the person's plan.
- 10. In the event that a person's employment or other activities were chosen pursuant to 9.b., Defendants shall assure that a full description is made of more desirable employment or other activities for that person. That description shall be used by the Defendants for the purposes of locating or developing the employment or other activities for the person.
- 11. Defendants shall continuously locate, secure, fund, and develop employment or other activities identified pursuant to paragraph 9.b.
- 12. On an annual basis, Defendants shall assure that employment or other activities are developed for one-third of persons whose current employment or other activities are provided under paragraph 9.b. Priority development shall occur for those persons who have waited for 24 months or longer.

- 13. The Defendants shall maintain a Resource Directory that includes information sufficient to explore eligibility and accessibility by persons to residential and program services throughout the state. The Defendants shall update the Resource Directory annually.
- 14. While the development of safe, healthful and integrative community resources for persons who live at Pineland Center shall remain a priority for the Defendants, such development shall not proceed without simultaneous development of similar resources for persons currently residing in the community but needing similar resources for their own well being.

## XI. Family and Respite Services

- 1. Defendants shall offer supports to persons and their families so as to maximize community integration, consumer and family control, and flexibility based upon the person's needs and desires, as expressed through the planning process. Defendants shall recognize and build upon the natural supports available to an individual, such as friends and family.
- 2. By September 30, 1994, Defendants shall provide family support services through an individualized family support program.
  - a. The Family Support Program shall allow families the flexibility to determine the types of services and supports needed by the family and shall include but not be limited to such options as informational materials, support groups, training, planning, service coordination, recreational options, counseling medical and dental services, transportation, adaptive equipment, in-home services, and crisis services.
  - b. Defendants shall submit annual budget requests calculated to be adequate for the development of a comprehensive system to meet the needs of families including persons with mental retardation.
- 3. By December 30, 1994, Defendants shall develop informational materials regarding DMR services. These materials shall be distributed to families currently accessing the Family Support Program. These informational materials shall also be made available to families who may not currently be aware of family support services by making the materials available to state and private agencies, employers, health care providers, and at other appropriate locations families may access.
  - a. Informational materials shall include at least the following; a description of the Family Support Program, services provided by DMR, advocacy services for the person and the family, family to family information sharing, information on crisis and respite services, the availability of funding to support families, and information on the services of other state and private agencies where families may receive support.
  - b. Any training offered by Defendants shall be made available to families. Defendants shall also continue to support family support conferences.
- 4. By December 30, 1994, respite services shall be available to families. These services shall include inhome staff support, a mechanism to pay neighbors and relatives to provide respite support, and out-of-home respite. The type of respite service used shall be determined by individual families.
- 5. The minimum amount of respite services available per family desiring it shall be at least 12 days each year. Wherever possible and desired, respite shall be provided in or near the person's home.

6. Defendants shall maintain records of requests for family support and respite services and records of waiting lists for such services. Defendants shall provide such information annually to the Legislature and Plaintiffs.

## XII. Appeals Process.

- 1. All persons and/or their representative shall have the right to grieve any action or inaction of the Defendants related to or involving rights afforded by, or arising under, this judgment. Private guardians and persons without a guardian must consent to any appeal by a correspondent or advocate.
- 2. Grievance rights shall be stated in language that is easily understood and in bold print on all notices or decisions issued by Defendants to any person, including notices relating to the personal planning process and to the provision of, or failure to provide, services. Grievance rights shall include the address and telephone number of the Office of Advocacy.

#### 3. Informal Review.

- a. If a person or his/her representative has a grievance as described above, any such grievance shall be duly noted in the person's record. It need not be in writing. The Individual Support Coordinator or agency staff person receiving the grievance shall make reasonable effort to ensure that the person and his/her representative, if any, are aware of their grievance and appeal rights. It is then the obligation of the Individual Support Coordinator to work expeditiously toward resolving the matter. If the grievance is not immediately resolvable, the Individual Support Coordinator shall inform the person and/or his/her representative that the grievance will be reviewed by the Regional Manager.
- b. Within five (5) working days of any grievance, if the grievance is unresolved, the person's Individual Support Coordinator shall notify the Regional Manager and the Office of Advocacy of the grievance and shall supply the Regional Manager and the Office of Advocacy, upon request, with whatever documents or information are necessary to understand the grievance. The Regional Manager has the right to speak to the person and/or his/her representative in order to clarify the nature of the problem or to seek out other information as may be necessary to a fair understanding of the issue being presented. The person and/or his/her representative may engage the services of the Office of Advocacy at their discretion. The Regional Manager, after consultation with the Division Director, shall provide a written decision regarding DMR's position on the grievance within five (5) working days of receipt of the initial notice of grievance.
- c. The written decision by the Regional Manager shall explain, in language that is easily understood, the Regional Manager's understanding of the issue, the nature of the grievance, his/her decision, and a statement regarding the reason for the decision. The decision shall also state, in language that is easily understood and in bold print, that the person and/or his/her representative has the right to appeal the decision by so requesting in writing, to the Individual Support Coordinator or the Regional Manager within ten (10) days of receipt of the decision. The request for appeal shall explain, if possible, the reason why the person or his/her representative is objecting to the Regional Manager's decision, but this explanation is not necessary to the appeal and shall not be grounds for dismissal of the appeal.

- 4. Formal Review/Appeal.
  - a. If an appeal is requested, the Individual Support Coordinator or Regional Manager shall immediately forward the request to the hearings unit which shall schedule a hearing within ten working days of receipt of the request from DMR. The hearings unit shall give notice of the hearing to the person, the person's representatives, the person's Individual Support Coordinator, and the Regional Manager. 'The hearing may be held at a regional DHS or DMR office, although the parties may mutually agree to hold a hearing at a location which can provide more suitable accommodations or level of comfort for the person.
  - b. The hearing shall be held in accordance with the rules of the hearings unit. Within three working days of the administrative hearing, the hearing officer shall forward his or her written decision to the person, the person's representatives, the person's Individual Support Coordinator, and the Regional Manager.
  - c. The hearing officer's decision shall constitute final agency action for purposes of Rule 80C of the Maine Rules of Civil Procedure unless final decision-making authority has been reserved by the Commissioner.
- 5. Should a person appeal pursuant to Rule 80C and be successful on appeal, counsel for the person may be awarded a reasonable attorney's fee in addition to his/her costs if the Defendants' position on appeal was not substantially justified.

## XIII. Consumer Advisory Board.

- 1. An eleven-member Consumer Advisory Board shall be maintained, and its responsibilities shall include evaluation of alleged dehumanizing practices, promotion of normalization, examination of violations of individual rights, and monitoring the Defendants' compliance with this decree until such time as the decree may be terminated. The Board shall submit minutes of its monthly meetings and at least annual written reports to the Director and to the Commissioner. Annual reports shall be available to other Plaintiffs, family members, and all individuals who support persons with mental retardation.
- 2. Membership on the Consumer Advisory Board shall include, but is not limited to, class members, relatives of class members, community leaders, and a representative from the Office of Advocacy.
- 3. The members shall be appointed by the Commissioner for staggered terms not to exceed two years. At least three nominations to the Commissioner shall be made by majority vote of the CAB at least 30 days prior to the expiration of a member's term. Should the Commissioner not accept the recommendations of the Board regarding nominees for Board positions, the Board shall submit a minimum of three alternative nominations to the Commissioner. A member whose term has expired may continue as a member until the Commissioner appoints a successor.
- 4. Consumer Advisory Board members and its staff shall have direct access to all living, work, and program areas, and to all living work, and program area records related to all persons, other than personnel records, and to the personnel of any institution, facility, agency or other provider administered by the Defendants or where any person resides or participates in work or a program.

- 5. There shall be regional committees of the Consumer Advisory Board with one additional committee for Pineland Center as long as Pineland Center remains open. A member of the Consumer Advisory Board shall serve as chair of each committee and shall nominate as members of his/her committee, for approval by the Consumer Advisory Board, at least four correspondents who reside or work in the region or, for the Pineland committee, correspondents for persons residing at Pineland. Members must be correspondents. The total number of members on any regional committee shall be at least four, but shall otherwise not exceed a ratio of one member for every fifteen correspondents in that region or, for the Pineland committee, one member for every fifteen correspondents for Pineland residents.
- 6. A representative, or representatives, of the Defendants shall attend meetings of the Consumer Advisory Board if a timely request is made by the Board.
- 7. The Consumer Advisory Board's responsibilities shall include recruitment, approval, training, supervision and support of volunteer correspondents for class members who have no guardian or family member active in their lives. Defendants shall cooperate with the Consumer Advisory Board in its recruitment of volunteer correspondents. The Consumer Advisory Board shall provide names and addresses of volunteer correspondents to Defendants quarterly.
- 8. The Consumer Advisory Board shall maintain and update a policy and training manual for volunteer correspondents and members of regional committees that shall include a policy regarding protection of confidential information. A copy of this manual, and any updates, shall be provided to Defendants for review and comment.
- 9. Matters may be brought before the Consumer Advisory Board by any individual or organization including Consumer Advisory Board members, DMR clients, residents of Pineland Center, parents, guardians, advocates, or employees of Pineland Center, DMR, or any other State employee. No individual shall be subject to counseling, discipline, or reprisal for bringing a matter to the attention of, or for giving information to, the Consumer Advisory Board.
- 10. DMR shall provide facilities required by the Consumer Advisory Board. DMR shall reimburse the reasonable expenses of the Consumer Advisory Board members, Regional Committees, and the Assistant to the Board, and the salary Of the Assistant to the Board, for carrying out their responsibilities.

## XIV. Standards for Auditing the Decree.

- 1. The Defendants and the Consumer Advisory Board shall initiate an annual review of compliance with the standards set forth in this decree. The review shall take the form of statewide public hearings. The Audit Committee shall consist of a representative of DMR, a representative of the Consumer Advisory Board, and a third person selected jointly by DMR and the Consumer Advisory Board.
- 2. Prior to the review process, the Defendants shall give notice of the intended review and of the public hearings.

- 3. At least 20 days prior to commencement of the review process, the Defendants shall:
  - a. Issue a press release and cause notices to be published in the major daily newspapers of the State of Maine and issue a second notice in the same manner at least 20 days before any scheduled public hearing.
  - b. Post notices in the central office of the Department, at regional offices of DMR, and at Pineland Center as long as the Pineland serves individuals with mental retardation.
  - c. Notify by mail all organizations with interests in persons with mental retardation such as parent groups, consumer groups, provider groups, advocacy groups, and any other person or organization requesting formal notice.

## 4. The notice shall:

- a. State the purposes of the audit.
- b. State the time and place of any scheduled public hearing.

## 5. Public Hearings and Collection of Data.

- a. The Audit Committee shall determine the number and location of public hearings, making sure that the hearings allow for public comment throughout the state. The Audit Committee shall produce minutes of each hearing that note all public comments.
- b. The Audit Committee shall allow for written submissions in lieu of public testimony and may collect any other available information relevant to decree compliance including, but not limited to, information from the Defendants, from the Consumer Advisory Board, and from providers.
- c. Upon written request of all three Committee members, Defendants shall hire consultants to assist the Audit Committee with the analysis of data and/or analysis of decree compliance.

# 6. Committee's Report.

- a. After the public hearings, collection of other data, and analysis of the information collected, the Audit Committee shall prepare a written report which shall include:
  - i. A description of items discussed and commented upon by the public.
- ii. A description of other data collected and any consultants' reports generated or reviewed.
- iii. The Committee's findings, conclusions, and recommendations for corrective action required, if any.
- b. The Audit Committee's report shall be made available for inspection and copying at the central office of the Department and at regional offices of DMR. The report or a summary of the report shall be made available to all persons or organizations upon request. Minority reports may be developed and made available when needed.

#### 7. Corrective Action.

- a. If the committee's report recommends the need for corrective action, the Defendants shall develop and implement a plan of correction which fairly addresses the findings and conclusions of the report. The plan of correction shall be completed within three (3) months of receipt of the report. The plan shall identify appropriate time frames and resources required to implement said plan.
- b. Any developed plan of correction shall be made available for inspection and copying at the central office of the Department and at all regional offices of DMR. Any plan of correction shall be mailed to counsel for the Plaintiff class and to all individuals or organizations upon request.

## XV. Budget.

- 1. Defendants shall use any budget savings generated by the closure of Pineland Center for both the provision of community services to the clients of the Division of Mental Retardation and to implement the provisions of this decree. Any additional savings generated by said closure, if available, shall be used for the provision of services to individuals with mental retardation.
- 2. Defendants shall take all steps necessary to ensure the full and timely financing of this decree, including submission of budget requests which are calculated to meet the terms of this decree.

#### XVI. Miscellaneous

- 1. The Defendants shall have an annual written agreement with each provider of residential and program or work services. The written agreement shall assure the following:
  - a. Assessment of the person's satisfaction with his/her home, program, workplace, supports, and services shall be the primary indicator of providing quality services and supports.
  - b. The provider's agreement to follow all applicable laws, rules, and regulations.
  - c. The right of the Defendants and their employees and agents to reasonable access to the home or program of all persons and to the records of each such home or program.
  - d. An outline of the provider's financial reimbursement and responsibilities.
  - e. Participation by providers in the planning process.
  - f. Compliance with each person's service agreement, as outlined in the planning process.
  - g. A description of the sanctions should the provider not meet the terms of the agreement.
  - h. That each provider develop and implement a quality assurance plan and make such available to the DMR.
- 2. Defendants shall maintain a meaningful table of organization, clearly defining areas of responsibility and accountability by position.
- 3. Defendants shall maintain current and meaningful written policies and procedures for the operation of the Division of Mental Retardation.
- 4. Defendants shall maintain and use an updated mailing list, including addresses and telephone numbers of all persons, their correspondents, and their immediate families in order to assure all necessary information and communications can be distributed.
- 5. Correspondents shall have access to all living, work, and program areas and to all records related to the person or persons for whom they are the correspondent, other than personnel records, and to the personnel of any institution, facility, agency or other provider administered by the Defendants where the person or persons for whom they are the correspondent resides or participates in work or a program. Correspondents do not have access privileges to information or records confidential to any person or persons for whom they are not the designated correspondent.

- 6. Defendants shall provide training for their staff in the terms of this decree. A program to provide such training shall be in place within 6 months of the date of this decree and shall be provided periodically as deemed appropriate by the Defendants. Defendants are also responsible for assuring that providers with whom Defendants have a legal relationship provide training as well.
- 7. Defendants shall maintain and enforce rules, pursuant to the Maine Administrative Procedure Act, regarding the use of restraints and behavioral procedures. Rules must include but not be limited to:
  - a. Definitions;
  - b. Prohibited procedures;
  - c. Reporting procedures; and
  - d. Monitoring procedures.
  - e. The rules shall also require that the Defendants provide training for their own staff in this area and that they shall update employee training on a regular basis. To the extent of capacity, initial training and updates shall be open to individuals who support persons with mental retardation. The Defendants shall ensure that employees of providers are also trained regarding the rules on restraints and behavioral procedures.
- 8. Defendants shall ensure that an advocacy system adequate to meet all persons' needs is in place.
- 9. Defendants shall develop a comprehensive quality assurance plan by September 1, 1994. Defendants shall submit this plan to the Plaintiffs for review and comment. Defendants shall implement this plan by October 28, 1994, unless funding requirements necessitate additional appropriations. In that case, Defendants shall seek such funding at the earliest practical time and shall implement the system to the extent possible, and fully implement the system when such funding becomes available.
- 10. Defendants shall engage in discussions with the Department of Human Service's Division of Licensure and Certification in order to address potential conflicts between compliance with Medicaid rules and the prompt identification of unmet needs. Defendants shall seek a Memorandum of Understanding with the Division of Certification and Licensing regarding how ICF/MR facilities can identify class member unmet needs, develop interim plans to meet those needs, and still stay in compliance with the ICF/MR regulations.
- 11. Defendants shall make every effort to ensure that a person in the Governor's Office is identified and will be responsible for being knowledgeable about the terms of this decree.
- 12. The services described in this decree define the minimum level of services to be provided by the Defendants to the Plaintiff class and are not intended to otherwise limit Defendants in the care and support of Maine citizens with mental retardation.

Dated at Portland, Maine, this 28th day of September 1994. GENE CARTER, Chief Judge UNITED STATES DISTRICT COURT

## Seen and Agreed to:

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